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ABSTRACT

This paper examines transition from school to post-school activities for students with chronic illness and disabilities, with reference to: four legislative acts that impact transition services, seven legislated implementation mechanisms, seven outcomes areas, and a social system for evaluating services to transitioning youth. Transition legislation addressed includes Public Law 94-142, the Education of All Handicapped Children Act; the Individuals with Disabilities Education Act of 1990; Section 504 of the Rehabilitation Act of 1973; and the Americans with Disabilities Act of 1990. Mechanisms that are incorporated into this legislation to ensure critical transition outcomes include, among others: individualized transition services, inclusion of transition services in Individualized Education Programs, coordination of school and adult services, and individually determined outcomes. Transition services focus on employment, training and education, financial/economic, recreational, social relationships, independent living, and residential outcomes. A multiple systems approach is recommended for meeting the information, support, and service needs of students and their families. This social systems framework consists of four mutually interactive levels: student and family, program, organization, and community. Two student and family scenarios illustrate the transition process from a social systems perspective. The paper concludes that service professionals and other team members need to function as facilitators or knowledgeable advocates, rather than "experts" in helping individuals with disabilities make decisions for themselves. (Contains 12 references.) (JDD)

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Moving out into the World:
Transitions from Adolescence to Adulthood
for Students with Chronic Illness and Other Disabilities

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Abstract

Recent legislation has resulted in major changes in the delivery of educational and social services to persons with special needs. This paper reviews transition-related legislation, as well as the transition mechanisms and outcomes mandated as a result of this legislation. Two student and family scenarios are used to illustrate the transition process from a social systems perspective.

The year Mary was in my class was the first time she'd been able to attend school for more than two days a week: She was 14. At least twice a year she would miss a month or more, but never long enough to engage homebound instruction. Academic programming for her had been almost impossible. Skill attainment was extremely scattered and there were huge developmental gaps. Her language patterns were immature and she couldn't always make her needs and wants known. Mary's social interaction with peers consisted of insults designed to get their attention, followed by bewildered tears when others eventually sought revenge. Mary consistently tested out in the high normal intelligence range but was performing at primary grade levels. It was all very discouraging.

American youth with special needs have the same aspirations as all other youth. They wish to live, work, and recreate in the community with their friends and family. They want to be part of the American dream. Unfortunately, history suggests that most of them do not find jobs, live independently, or find desired opportunities for recreation.

Over the past two decades, major changes have taken place in the delivery of educational and social services to persons with special needs (Rusch, DeStefano, Chadsey-Rusch, Phelps, & Szymanski, 1992). Thus, the era of specialized and isolated service delivery is over. Further, passage of transition legislation signals a recognition of the lifelong needs of individuals with disabilities and the beginning of an integrated programs model. As a result, many young adults with disabilities are now able to live, work, and play in our towns and cities--just as many of us expected to do when we were growing up. This legislation defines transition from school as:

> a coordinated set of activities for a student, designed within an outcome-oriented process, that promotes movement from school to post-school activities, including postsecondary education, vocational training, integrated employment, continuing and adult education, adult services, independent living, or community participation. (Transition Summary, 1993, p. 2)

In this paper we will examine transition with reference to (a) four legislative acts that impact transition services, (b) seven legislated implementation mechanisms, (c) seven outcome areas, and (d) a social system for evaluating services to transitioning youth.

Transition Legislation

P.L. 94-142. Universal provision of services to students with special needs began in 1975 with P.L. 94-142, the Education of All Handicapped Children Act. As a result of this legislation, every special education child is guaranteed educational services in the *least restrictive environment*, generally determined as the local school district. Further, all special services are documented on an Individual Education Plan (IEP)--an annual program that is designed by parents, school personnel and, when appropriate, the student. Services are guaranteed through rights of due process and parents may challenge decisions or IEP placements.

This act marked a new trend in increased decision-making power for parents and consumers with disabilities. At the same time, the IEP meetings initiated many of the collaborative planning practices that have come to characterize services to individuals with disabilities, including mandated transition services.

IDEA. Taking PL 94-142 a step further, the Individuals with Disabilities Education Act of 1990 (IDEA; P.L. 101-476), addresses the problematic discontinuity of services and eligibility procedures from school-age to adult services. Thus, IDEA mandates post-school planning for special education students to begin no later than age 16, with the plans documented on students' IEPs. This planning must list interagency linkages and responsibilities for each team member, the student and parents, the school, and other service agencies necessary to accomplish the transition outcomes.

This legislation addresses special education students as defined by specific disability categories. For example, orthopedically or other health impaired are two of the categories that include students with chronic illness (Kendall, 1991). However, the broad impacts of chronic health impairments may not fit the required acuteness of any

one definition (Biehl, 1987). Consequently, unless their condition adversely affects their educational progress, children with chronic health impairments are not included.

Section 504. Many of these ineligible children may receive services under Section 504 of the Rehabilitation Act of 1973, however. In accordance with this piece of legislation, students receive personal and assistive technology interventions if they have a physical or mental impairment that limits one or more major life activities (Arizona Department of Education, 1991). Amendments in 1986 and 1992 have increased opportunities for supported employment (community employment with monitoring and support), expanded independent living programs, and streamlined transition from high school to rehabilitation programs.

ADA. The Americans with Disabilities Act (ADA) of 1990 is the most recent major piece of legislation to have expanded transition opportunities for individuals with disabilities by addressing their rights. This bill guarantees access to employment and community facilities and mandates reasonable accommodations except in cases of undue hardship. As a result, whether private or public, all community postsecondary training, employment, and recreation facilities are now available for transition activities.

Through guaranteed access and accommodation, these four pieces of legislation have guaranteed educational, personal, and transition services for special education students with special needs and have expanded transition opportunities. For example, a student like Mary qualifies for special education services because of her significant academic delays. Since she is 14, a transition plan is not required; however, because of her health and attendance problems, her IEP should begin addressing independent living and future career choices as well as remediating her academic and social skill deficits.

In the following section we will examine the mechanisms that are incorporated into IDEA to ensure the critical outcomes stipulated in the transition definition: provision of educational activities, integrated employment, independent living, and community participation.

Transition Mechanisms

As mechanisms for achieving transition outcomes, IDEA mandates seven conditions based upon current educational best practices:

1. transition services are based upon the needs, preferences, and interests of individual students;
2. IEPs will include statements of needed transition services beginning no later than age 16;
3. school and adult services will coordinate efforts to promote movement into postschool activities;
4. coordinated, community-based experiences and instruction will develop employment and adult living skills;
5. outcomes will be individually determined to include postsecondary education, vocational education, vocational training, integrated employment, continuing and adult education, adult services, independent living and community participation, as needed;
6. evaluation of transition services will be based on student adjustment in the postschool and community environments; and
7. the educational agency is responsible for monitoring and assuring delivery of transition services with responsibility to reconvene the meeting and renegotiate any unmet goals.

Such coordinated and collaborative planning is particularly valuable for students with complex needs requiring multiple service specialists. Thus, the interactive process assists these specialists in managing the various systems and disciplines involved (Pacer Center, Inc., 1992), and prepares all team members for periodic acute healthcare needs as well as more chronic needs (Biehl, 1987).

Mary has severe asthma and could benefit from a concerted team effort in managing the impact of this condition on her academic achievement and preparing her for future

changes. Team members would include Mary (at age 16, if not before), her parents, her teacher, the school nurse, an adult service agency (such as the Department of Rehabilitation), her medical specialist or family doctor, and an adult education or community college representative, as appropriate. An important transition outcome will be to introduce Mary to the personnel and agencies she will come in contact with when moving from student or pediatric services to adult-oriented services. It is important to begin the eligibility process as early as possible to avoid any service delays. The IEP team may form the basis for a long-term personal support network as Mary becomes increasingly independent. Mary's school will monitor the transition responsibilities until she graduates and will reconvene the IEP meeting if goals are not met.

While the legislation mandates these best practices to ensure interagency cooperation and collaboration, specific transition outcomes are less well defined. In the next section we look at a series of outcomes that need to be addressed in transition planning.

Transition Outcomes

A number of options have been suggested (Transition Summary, 1993; Wehman, 1992) for addressing the outcomes contained in the transition definition: postsecondary training, integrated employment, independent living, and community participation. For example, the California State Department has divided these outcome areas into seven topics that are listed below along with options within each (California School for the Deaf-Riverside, 1992).

1. Employment: includes work sites ranging from competitive employment (in the community), to supported employment (routinely monitored), and volunteer work;
2. Training and Education: a variety of vocational services and agencies, school work experiences, and postsecondary education programs;
3. Financial/Economic: wages and benefits, income taxes, social services, insurance, and money management skills;

4. Recreational: use of leisure time, sports and fitness, and stress-management activities;
5. Social Relationships: socialization and friendships ranging from work acquaintances to close friends, personal relationship skills, support systems, and requisite communication skills;
6. Independent Living: home management and maintenance, consumer services, community awareness, survival and safety skills, personal management, health services (medical, dental, mental), sexuality and family life, adult rights and responsibilities, and advocacy and legal services; and
7. Residential: includes remaining in the family residence, shared living, independent living, supervised group living (dormitories), and residential care facilities.

Choices among these areas are based on individual student needs and preferences. For example, Mary's Training and Education would address developmental gaps, specific interaction interventions would be listed under Social Relationships, Independent Living would include increased responsibility for health and other decisions, and Employment would identify potential careers and preparatory work experiences.

An annual meeting cannot address all the information, support, and service needs of both students and their families. In the following section we examine solutions generated by using a social systems perspective. A multiple-systems approach will generate more expansive solutions to community barriers by making an environment more responsive and supportive of an individual with unique needs.

Issues and Solutions

Rappaport (1977) introduced a systems-level approach, which was applied to students and workers with disabilities in 1985 (Rusch, Enchelmaier & Kohler, 1993;

Rusch & Mithaug, 1985). The social systems framework consists of four mutually interactive levels:

1. student and family, usually the focus of interventions and programming;
2. program, responsible for implementing the interventions;
3. organization, the agency network that collaborates with the primary program in service delivery; and
4. community, including services and opportunities available including transportation, employment, recreational, and transportation.

We will use this system to identify solutions at every level for Mary and her family and for an additional student, Alan. Only by including all four levels and the unique interactions and contributions of each can we adequately meet the needs presented by these students and their families.

Alan developed recurrent headaches once again, a periodic complaint due to his scoliosis. Just 21 years old, Alan had started a training program as a new client of the Department of Rehabilitation. But he was neglecting to call in to report that he was ill, and he missed a meeting with his rehabilitation counselor. This was a surprise because only two months ago he successfully completed a one-year career and training program in a supervised apartment setting. If it hadn't been for his mother dragging him to the next meeting, he would have been dropped as a rehab client and left without further training or support services.

Student and family level. Mary's family is very supportive of her healthcare needs. Since an aunt also has severe asthma, the family is acquainted with both her routine and her acute needs. In addition, the aunt is a source of emotional support and encouragement for both Mary and her family.

The family has expressed concern about the costs of Mary's healthcare, however. Their income level exempts them from a number of federal programs, yet is insufficient

to cover all costs. Consequently, they are reluctant to seek medical services as often as needed. They hope that someone at the school can help them.

Alan's family is also supportive but finds it difficult to give him advice. Consequently, they have asked for assistance in enabling Alan to make responsible decisions, especially with respect to realistic timelines, employment and financial support. They are willing to support him until he leaves home, if he is willing to contribute.

Alan and his girlfriend wish to get married soon and both families are in agreement. He is having difficulty fitting his dreams into reality, however. For example, he is not concerned about being unemployed and thinks his brother will give him his house when he moves. Further, when making career choices, Alan tends to overestimate his physical endurance, which is limited due to his scoliosis. Alan needs help in a way that will further his growing independence and self-determination.

Program level. Mary's IEP team will develop educational goals to address developmental gaps, social skills training, and increased opportunities for interacting with peers. Although only 14, Mary needs to take an increasing initiative for monitoring her own health, using her medications appropriately, and seeking information from her doctor.

Her school program includes introductory work-exploration activities which give her opportunities to interact with co-workers and supervisors. Specific career, training, and residential options will be addressed as she gets older. The school is not able to provide Mary's family with resources or information about financial assistance. Instead, they plan to contact other agencies that may be able to offer help.

Alan was a special education student because of severe learning disabilities. He is now receiving training through the Department of Rehabilitation and can continue to do so provided he fulfills his obligations with them. If not, he will be left to his own and his family's resources. Although possibly an effective lesson in real-life consequences, it is

not cost effective if Alan remains unemployed, supported by either Welfare or Supplemental Security Income. Once without work, unemployment rates for individuals with disabilities increase (Mithaug, Martin, Agran, & Rusch, 1988). As a result, Alan's compliance with his rehabilitation program is becoming a critical life decision that must be addressed at other levels.

Organization level. Mary's IEP team members are pursuing information about financial support available through other agencies. Also, her medical specialist may know of a parents' group that could assist Mary's family in identifying financial resources in the community as well as addressing other issues as Mary moves into adulthood. Further, a patient support group puts Mary in touch other peers, thereby improving her social skills in addition to offering opportunities for sharing some of her frustrations.

Mary's team wants to know specifics about Mary's prognosis, symptoms they should be aware of, and possible interventions to reduce Mary's absenteeism. Such information will influence career decisions, including the "health" of potential work environments and the physical demands of the job. Mary's parents have agreed to ask the aunt to meet with the team as she is a potentially useful resource in guiding future decisions.

Alan's rehabilitation counselor has invited members from the previous IEP team to assist Alan and his family with timelines and decision-making strategies. At some point, the team may wish to do joint planning with Alan's girlfriend, who is also a rehabilitation client, to help the couple develop realistic goals and plans.

There is some concern about Alan's headaches. For example, if they are indicative of a deterioration in his overall health, they may impact his need for future career and support services. On the other hand, the headaches may be symptomatic of Alan's anxiety over his new adult status and independence. In this case, he needs constructive reassurance; for example, a mutually developed sequential plan that is periodically reviewed may provide a sense of structure without compromising Alan's sense of self-

direction. Further, Alan's medical specialist may know of a support group that could help him learn about, and cope with, his physical limitations and make realistic, yet optimistic life choices.

Community level. The financial dilemmas facing Mary's family are not unique; healthcare for families in this country generally depends on the parents' employment. Assistance programs frequently set low income-level criteria. However, Mary's healthcare costs are higher than average and, along with her current absenteeism, could present significant barriers to employment. Thus, without changes in current policy, Mary may not be able to get the insurance, or the job she needs, to be able to pay for her healthcare. Financing healthcare for individuals with disabilities is an issue that must be resolved at the policy and legislative level. To do so requires information and action by consumers, their families, and their advocates.

Although Alan was fortunate to have participated in a supervised apartment- living and career program, he would benefit from additional training and opportunities in a program of gradually decreasing supervision and support. The school has considered opening a second-year program off campus, but needs interagency and state-level help to secure the facility, train and certify the staff, and write the grant. The school has made initial state-level contacts but is currently caught up in a districtwide program review and, therefore, has not had time to pursue this issue.

Unlike many individuals with disabilities, Alan is eligible for rehabilitation services. Since, funding is allocated locally, resulting services vary with locale. Further, counselors are evaluated based on numbers of clients placed in employment. Although this may be an efficient and effective way to retrain returning veterans, it is not an effective way to deal with the diverse needs of individuals with disabilities now guaranteed access to employment and community participation. Individuals who are determined to be ineligible or who lose their eligibility have no other service agency to

turn to. Without training options and assistance in finding employment, their only option is to seek public assistance -- a burden for taxpayers that only worsens over time.

Individuals at all levels of the social system need to provide local-, regional-, and federal-level decisionmakers with specific information about problems as well as suggestions for change. The legislation guaranteeing access is having ever-broadening effects; at the same time, however, it is making more apparent the tremendous gaps and the lack of a unified and consistent service delivery system, particularly after adulthood.

Conclusion

This paper has examined various issues related to transition, all of them pointing to the need for service professionals and the entire community to work together to ensure full participation and independent living for young adults with disabilities. Team members will increasingly be asked to function as facilitators or knowledgeable advocates, rather than "experts," in helping individuals with disabilities make decisions for themselves and supporting them in these decisions. In many instances, we will need to identify solutions that extend beyond our own professional or programmatic resources and involve all four levels of the social system. Only if we work together will the time come when individuals with disabilities are truly empowered to lead their own lives in a community that is increasingly accepting and supportive.

References

Arizona Department of Education. Special Education. (1991). Section 504: A challenge for regular education. AZ-TAS themes and issues: A series of topical papers on special education. Phoenix, AZ: Author.

Biehl, R. F. (1987). In H. Wallace, R. Biehl, A. Oglesby, & L. Taft (Eds.), Handicapped children and youth: A comprehensive community and clinical approach (pp. 17-25). New York: Human Sciences Press, Inc.

California School for the Deaf-Riverside. (1992). Individual transition plan. Riverside, CA: Author.

Kendall, R. M. (1991). Unique educational needs of learners with physical and other health impairments. East Lansing, MI: Center for Quality Special Education Disability Research Systems, Inc. (ERIC Document Reproduction Service No. ED 342 186)

Mithaug, D. E., Martin, J. E., Agran, M., & Rusch, F. R. (1988). Why special education graduates fail: How to teach them to succeed. Colorado Springs, CO: Ascent Publications.

Pacer Center, Inc. (1992). Speak up for health: Young people with chronic illness and disabilities speak about independence in health care [Videotape]. W. St. Paul, MN: Armour Productions.

Rappaport, J. (1977). Community psychology: Values, research, and action. New York: Holt, Rinehart, and Winston.

Rusch, F. R., DeStefano, L., Chadsey-Rusch, J., Phelps, L. A. & Szymanski, E. M. (1992). Transition from school to adult life: Models, linkages, and policy. Sycamore, IL: Sycamore Publishing.

Rusch, F. R., Enchelmaier, J. F., & Kohler, P. D. (1993). Employment outcomes and activities for youths in transition. Manuscript submitted for publication.

Rusch, F. R., & Mithaug, D. E. (1985). Competitive employment education: A systems-analytic approach to transitional programming for the student with severe handicaps. In K. Charlie Lakin & R. H. Bruininks (Eds.), Strategies for achieving community integration of developmentally disabled citizens (pp. 177-192). Baltimore, MD: Paul H. Brookes Publishing Co.

Transition summary. (1993, March). NICHCY [National Information Center for Children and Youth with Disabilities], pp. 1-9. New York: NICHCY.

Wehman, P. (1992). Life beyond the classroom: Transition strategies for young people with disabilities. Baltimore, MD: Paul H. Brookes Publishing Co.